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Ethical Issues in Conducting Research with Deaf Populations

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Abstract

Deaf American Sign Language (ASL) users represent a small population at risk of marginalization from research and surveillance activities as a result of cultural, language, and ethical challenges. The Deaf community's view of deafness as a cultural identity, rather than a disability, contradicts the medical community's perception of deafness as a disease or deficiency in need of correction or elimination. These differences continue to have significant cultural and social implications within the Deaf community, resulting in mistrust of research opportunities.

Two particularly contentious ethical topics for the Deaf community are the absence of community representation in genetic research and the lack of accessible informed consents and research materials. This article also outlines a series of innovative strategies and solutions to these issues, including the importance of community representation and collaboration with researchers studying Deaf populations.

Cultural naïveté and lack of language fluency create a host of barriers and ethical dilemmas for many health researchers who work with minority, underserved, and vulnerable populations. Collaborating with underrepresented communities requires researchers to demonstrate creativity, mutual respect, flexibility, compassion, cultural competency, and patience in their work. Deaf American Sign Language (ASL) users comprise a population of particular concern due to the marginalization they face as a result of communication, cultural, social, and language barriers. These challenges have historically isolated the Deaf community from a variety of beneficial health education and outreach programs, disease surveillance, and health research resulting in health inequities and limited health care access.[1-7]

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Few health researchers understand the cultural values held by the Deaf community or know ASL. The lack of linguistic and cultural concordance places the population at high-risk for poor research engagement and inaccessible informed consent processes and research materials. This perpetuates a long-standing history of fear, mistrust, and frustration of Deaf ASL users with biomedical research.[8]

The Deaf ASL community refers to Deaf individuals who use ASL as their primary language, and constitute a group of individuals who identify themselves as a minority entity, with their own unique language and culture.[9,10] Deaf ASL users share a set of values, customs, attitudes, and experiences that contrast with the hearing world.[13] ASL is commonly misunderstood to be a gestural language or a visual "English" language representing spoken English. ASL contains its own syntax and language structure, which is distinct from English and does not have a written form. Approximately 500,000 Deaf ASL users are estimated to live in the United States.[11,12]

Despite increasing evidence of substantial health disparities within this population, the Deaf ASL community is largely under-studied and underserved. Deaf ASL users rarely participate in clinical research and surveillance activities in part due to: exclusion criteria, inaccessible informed consent processes, inadequate recruitment and engagement strategies, and culturally misguided genetic testing and engineering.[13-16] The principles of justice, respect for persons, and beneficence behooves public health researchers to address existing health inequities by promoting access and collaboration with Deaf communities. This paper follows the principles of ethical theory in outlining two key ethical issues along with potential strategies for health researchers to increase participation opportunities for Deaf ASL users to benefit from clinical research and surveillance efforts. The authors hope the paper will help researchers better understand the perspectives of Deaf community members on biomedical research.

The Fear of Genetic Testing and Engineering

Historically, deafness-related research has tended to focus on the elimination of deafness through the use of medical technologies and genetic engineering.[9,14] The eugenics movement (1880-1950) in the United States, Great Britain, and Germany provided some degree of moral permissibility of sterilizing deaf people with the intent of reducing "social burdens" and increasing the health of the human species through "better breeding."[10,17,18] Another movement called oralism, popularly promoted by Alexander Graham Bell, prioritized human speech over sign language and incorporating the use of speech reading and hearing amplification.[10,19] The lasting impact of the Eugenics and oralism movements and advancing medical technologies (e.g. success of hearing aid use and cochlear implants) have led to society's negative perception of deafness as a disability, rather than as a cultural identity.[10] The focus on deafness as a disability (i.e. the "medical model" of deafness) conveys conflicting values and the sense of inferiority to many deaf children and adults.[9,20,21]

Despite mostly well-intentioned efforts by health researchers and providers to mitigate or prevent hearing loss, deafness should not be viewed simply as a disease or disability, but

rather, from the community's perspective, as a unique feature or identity (e.g. skin color, height, or sexual orientation). Nowhere is this cultural clash more visible than in the advancement of genetic testing and engineering. The palpable threat of genetic testing and engineering to the Deaf community is unique to this minority population. There are no known genetic research studies that provide the potential elimination of a cultural attribute or phenotype valued by a particular minority or cultural group.

Despite the predominance of research on genetic etiologies of deafness and its syndromes, the Deaf community rarely receives an opportunity to express its views.[22,23] By failing to fully engage the Deaf community in dialogue about such findings and the research agenda, such research fuels fears that consequential genetic engineering may result in a substantial reduction of the number of congenitally Deaf individuals through prenatal genomic testing and genetic counseling.[24,25] Approximately 75–80% of the more than 400 identified deaf genes are recessive, with a smaller proportion being autosomal dominant (20%) and X-linked (2–5%), [2627] which results in a high proportion of deaf individuals born to hearing parents. The Deaf community has well-founded fears that prenatal screening could permit the opportunity for hearing parents to terminate pregnancies and/or elect the use of genetic engineering to avoid the birth of a deaf infant. The potential loss of future Deaf individuals has major implications for the viability of the Deaf culture.

The acquisition of ASL and Deaf culture is generally through peer-exchanges and Deaf schools (i.e. “horizontal cultural transmission”) and less so from parents (i.e. Deaf parents of Deaf children).[20] Horizontal cultural transmission differs from other minority populations, whose parents primarily transmit and share a similar language and cultural values to their children (i.e. through “vertical cultural transmission”).[20] Hearing parents, clinical providers, and medical researchers may lack familiarity with the Deaf community, further placing Deaf members at risk for medical and cultural misunderstandings. Middleton et al. (2001) found that hearing individuals are much more accepting of conducting prenatal testing to determine the presence of hearing loss than are Deaf individuals (49% versus 21%).[28] The lack of acceptance of testing reflects the ongoing mistrust of the medical community by Deaf individuals and the predominate notion held by the majority hearing population that the deafness is defective. Thus, the disconnect between the Deaf and hearing communities and much of the medical establishment involved with hearing testing, treatment, and counseling poses a continual risk to the Deaf community and fuels mistrust.

On the other hand, genetic research can benefit the Deaf community through the recognition of certain types of hereditary deafness associated with the risk of particular health outcomes. For example, some syndromic forms of deafness are associated with retinitis pigmentosa (e.g. Usher Syndrome), craniofacial dysmorphia (e.g. Treacher-Collins syndrome), long QT syndrome (e.g. Jervell and Lange-Nielsen syndrome), and renal abnormalities (e.g. Alport syndrome). There is even new recognition that certain deaf genes may even offer positive or protective effects against other conditions (e.g. Pendred syndrome appears to confer protection to Deaf individuals against hypertension and asthma).[29]

The majority of genetic causes of deafness are non-syndromic (e.g. Connexin 26), however, resulting in no other known health risk for Deaf individuals.[30] Research in deaf genetics is

complex, given the diversity of etiologies and syndromes, and the relatively high proportion of all human genes associated with hearing mechanisms (i.e. 1% of all human genes).[30]

Increasing Community Representation in Genetic Research

Population-based research needs to engage the Deaf community to learn about priority areas of research to improve health disparities and the social impact of the research on the Deaf community. The Deaf ASL community may hold different expectations and needs than what many researchers may anticipate. Deaf individuals are often aware of the biologic basis for some of their health differences but their focus frequently differs from researchers (i.e. existing health and social inequities, rather than deafness itself). It is critical that Deaf community members be encouraged to participate on community boards, research review committees, and research grant agencies to ensure appropriate cultural, linguistic, and ethical representation to ensure beneficence is achieved.

Furthermore, Deaf ASL users hold unique social and communication cultural norms,[20,31] which pose challenges for researchers to understand without directly engaging themselves in the community through a variety of actions (e.g. becoming fluent in ASL, attending deaf related events, respecting the Deaf cultural model). Researchers working with Deaf ASL users should ensure a presence in the community, including at important cultural events and relevant organizations to earn trust and credibility. Solutions within the Deaf community include researchers taking ASL classes, working closely with Deaf gatekeepers, and providing opportunities for community members to learn about relevant health topics and research.[14]

For example, Gallaudet University, a Deaf university, and the University of California Los Angeles conducted a variety of genetic research and counseling programs with a bicultural team of hearing and Deaf researchers and staff.[32,33] A research team consisting of Deaf researchers and staff can provide an additional element of cultural and language accessibility, in addition to trust, frequently necessary when researching complex or sensitive topics. Their particular research programs generated great interest among Deaf individuals across the country to not only identify deaf genes, but also to allow the researchers to explore the societal impact of advancing genetic testing on the Deaf culture.[33] In accord with the ethical principle of beneficence, the key is to ensure that genetic research in hereditary deafness maintains its focus on the acquisition of scientific knowledge and improvement of deaf people's health, not simply on the elimination of deaf people.[21]

Inaccessible Informed Consent

Informed consent requires that individuals receive adequate information to be able to make an informed decision to participate in research, that individuals understand the information provided, and that they are individuals able to make a voluntary decision.[34] Unfortunately, standard informed consent processes generally rely on written English forms, which are mostly ineffective for Deaf ASL users for multiple reasons. First, many Deaf ASL users often fail to accumulate factual knowledge resulting in significant gaps in basic information and limited “fund of information.”[21,35] The information gap occurs as a result of their inability to access auditory-based information and the scarcity of information resources

available in ASL.[20,21] Average written English proficiency[36] and health literacy[35] among Deaf ASL users are lower than the general population, which further precludes them from interacting with hearing researchers or asking questions during the informed consent process. Furthermore, the majority of informed consents are written at a level that requires a high school education or higher[37] which is problematic given 20% of deaf individuals have demonstrated fluency in written English,[38] and the average English reading level of deaf high school seniors is at or below a 4th-grade level.[36] The lack of comprehension can impair potential Deaf subjects' ability to truly consent and participate voluntarily in research.

Secondly, even among non-native English speakers with high educational attainment and good English proficiency, many individuals still require further explanation of the informed consent contents to achieve adequate comprehension.[39] Language and communication barriers play a significant role in creating difficulties in obtaining true consent among the general population. In one study, 40% to 80% of hearing English speakers with the capacity to consent still did not understand one or more aspects of the consent content,[40,41] whereas in another study 30% of consented research participants were completely unaware of their research involvement.[42] For limited English proficiency (LEP) populations, including Deaf ASL users, comprehension of research activities is thought to be much lower due to both language discordance and poorer health literacy. Even with the availability of on-site professional interpreter services, Schenker et al. (2007) found that Chinese- and Spanish-speaking hospitalized patients who do not speak English are less likely to have documentation of informed consent for common invasive procedures. [43]

Federal regulations governing human subjects research dictate "the information that is given to the prospective subject or the representative shall be in a language understandable to the subject or the representative."[4413,35,45] Sudore et al. (2006) demonstrated that to maximize the likelihood that consent information will be understood, informed consent should be delivered in the subjects' native language, regardless of proficiency in English.[39] It is difficult to address the complexity of health communication and informed consents without a first-hand knowledge of the targeted community's native language and cultural customs, norms, and values.[37,39,46,47] Unfortunately, very few studies evaluate informed consent processes and comprehension among those with limited English proficiency populations while none are available for Deaf ASL users.[48,49] This is concerning since many researchers and providers erroneously assume that ASL is based on English and that Deaf ASL users are proficient in written English and speech reading.[1,38,50] In addition to communication barriers, Deaf ASL users lack a written language which largely precludes many from the ability for them to simply read a translated informed consent. The lack of a written language is a unique challenge that places the Deaf population at additional risk apart from other minority populations.

Informed consent processes with Deaf ASL users need to be visualized in a much broader format than the commonplace written English consent forms. The use of language-concordant, accessible short videos and visual formats that do not rely on prose increase accessibility of informed consent forms. Joseph et al. (2006) and Murphy et al. (1999) demonstrated improvements in the recall ability and comprehension of consenting hearing participants with short videos and the use of pictures in their informed consents.[51,52] Sudore,

et al. (2006) also found that additional education (i.e. “teach to goal”) through the use of an interactive and educational strategy helped subjects to fully understand the necessary information, regardless of their educational attainment, language fluency, and social backgrounds.[39] Similarly, Kripilani et al. (2008) successfully utilized “teach-back” methods in informed consents with low-literacy groups.[53]

Culturally Appropriate Strategies to Improve Informed Consent Processes

When possible, research staff should be fluent in the populations’ native language and, if possible, be familiar with the culture of the population as well to help reduce mistrust, anxiety, and confusion during the consent process. These efforts have improved understanding and trust among Deaf individuals enrolled in studies affiliated with the National Center for Deaf Health Research (NCDHR) at the University of Rochester. Researchers at the NCDHR collaborate closely with their community partner, the Deaf Health Community Committee (DHCC), which consists of 15-18 representatives from the Rochester Deaf community to develop innovative ways to improve the comprehension of research materials and informed consents. Deaf subjects who enroll in NCDHR-based research studies receive informed consents in easy-to-read written English and either in ASL by a video or through an ASL-fluent research staff member. A critical step was the realization of the importance to present informed consent process in a dialogic fashion to improve both retention of information and ease of communication between the subject and the research team.[54,55]

This dialogic approach incorporates the traditional format of ASL story-telling between two Deaf individuals. As Pollard, et al. (2009) demonstrated, the key information outlined in an English document (i.e. informed consent form) is adapted and translated into an ASL script. Difficult to understand information is discussed in a conversational style between two or more Deaf actors.[16,56] The dialogic approach generates a short movie or a novella that is engaging, educational, and culturally affirmative, yet which conveys the same essential points found in the source material.

Informed consent, similar to other questionnaires and study materials, should be developed and piloted collaboratively with a community partner to ensure that the targeted population would understand the contents. The NCDHR and the DHCC partnered together to provide linguistic and cultural guidance and feedback on the informed consents and relevant research materials. This model of community-based participatory research (CBPR) provides an opportunity to address health issues in a variety of understudied minority populations, including Deaf ASL users.[7,14,57-59] CBPR integrates educational and social action in research through the active and equitable involvement of community members and researchers.[60] Benefits of CBPR include the empowerment of the community's ability to vocalize and address its health needs, the use of community's strengths and resources to initiate and conduct research, and the recognition of the community as a partner in research and public health.[61] The community is also provided an opportunity to share any reservations or concerns they may have regarding the informed consent processes or other aspects of research conduct.

Conclusion

Although many research studies involving Deaf and hard of hearing populations are associated with hearing loss and genetic research, the Deaf community, similar to many other minority populations, struggles with a number of socio-economic based health disparities, many of which are not directly associated with hearing loss. The Deaf community's health priorities may drastically differ from the goals of health researchers studying Deaf populations. Deaf community members should be provided with opportunities to vocalize or represent their community in agenda setting research meetings. It is critical that health researchers work closely with community members and organizations to learn about the health inequities that need to be addressed. Health research should ensure accessible research materials, including informed consent documents. Increasing accessibility of research studies to smaller populations such as the Deaf community helps to generate more representative findings while improving the equity of those who benefit from the advancement of health research.

Diversity in our population, regardless of race, ethnicity, language, culture, values, and hearing loss needs to be protected and respected in our health care and medical research settings. A more collaborative approach, using the principles of CBPR, beneficence, and justice, will allow for mutual respect between health researchers and the Deaf community and provide avenues for more culturally affirming health research to occur.

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